

9<sup>th</sup> August 2021

My journey with Early Onset Parkinsons

### **Part 1 of "No idea but hopefully many" – Year 1**

I have debated internally for a long time whether it is worth it to put my experiences down on paper. I don't want to draw attention to myself and I don't want to make myself out to seem in any way special...but for two reasons I have decided to write this. Firstly, for myself I want to keep a record of the progression of PD as a motivation to myself to keep fighting it day by day and (2) because I have learned some things about myself and the disease which may be relevant to others out there struggling to come to terms with it.

Before I tell my story and my learnings it is important to set the scene and to start with some background below.

The brief topics I cover are (1) what makes me lucky, (2) the background to my PD, (3) my emotions, (4) the medication and (5) the symptoms and (6) the final part is the important one – what I have learned so far.

I want to clarify AGAIN that I am not a professional in this field, I have no medical advice to offer, and I have had some huge advantages so please keep all of this in mind.... with a pinch of salt hopefully there is something you can take from this.

#### **(1) Lucky/Blessed**

At 46, I am extremely lucky, and I don't believe my situation is comparable to others out there. I have been blessed with many things going in my favor including:

- a. An amazing, supportive family across the board from my wife (who probably has it much harder than me), kids, parents, in laws etc
- b. I live in a country with great health care and because of my specific story I got access quickly to the best. I have and have had some fantastic doctors!
- c. I am financially ok meaning I have been able to afford supplements, meds, acupuncture, yoga etc (although my financial planning has been impacted majorly 😞)
- d. A work place and bosses who let me at the start have the time off to get back on the road to dealing with this and a great team around me who have jumped in to help
- e. I have a strange sense of humor (my kids would say a word far stronger than strange) that I think helps me make some things better by seeing the funny, ironic side of things
- f. Finally, I am religious out of choice and have a true belief that my condition is for a reason. I may not understand the reason but there is one and that means I must have the capability to deal with it (you may not agree but that's my faith). This means that on a certain level I am glass half full person by DNA. Let this not mean I am not scared of the future having seen others with PD but it is my test and it is up to me to stay healthy for as long as possible

I don't take these for granted and I know that I have major positives in my direction!!

## **(2) History/Background**

So the story so far before the lessons I think are relevant (for a detailed medical overview of the onset you can look at this Lancet article on my early days

[https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(20\)30305-7/fulltext](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(20)30305-7/fulltext) )

In brief I was a very early sufferer of Covid-19 in March 2020 (Patient 305 in Israel). I recovered after a couple of weeks of time spent at a hospital (all patients were being taken to hospital at the time) and a Corona Hotel. Minimal symptoms (cough, asthma, loss of smell, muscle ache).

A few weeks post recovery I started to get strange symptoms – my handwriting deteriorated, my balance was off, cognition and coherence were impaired, sight was blurred, a constant need for the toilet, when the doctor checked me I couldn't touch my finger onto my nose or stand up with my eyes closed for more than a second without falling down. To cut a long story short after 9 days in hospital and literally tens of procedures including a DaTscan (in fact two because I had a second opinion) I was diagnosed. Genetic testing ruled out a genetic link and to my knowledge I had not noticed any early warnings before Covid. That's the last I'll say about Covid – whether there is a link between it and PD is something no one at the moment can answer.

## **(3) Emotions**

I am a practical person by nature and in general have a positive outlook and I have tried to maintain it. I won't pretend however it has been easy even if a friend once joked that emotionally I am like an "empty tin can".

The truth of how I felt on diagnosis is mixed. I was completely shocked that I had been diagnosed with Parkinson's, but it was also mixed. I knew something was really wrong, so I had conditioned myself to expect the worst. At first, I thought I'd had a stroke or a tumor so I am not sure what was/is better and later as they investigated, they thought it may be Autoimmune Encephalitis which they ruled out after 6 weeks of IV Steroids (Week 1 every day and then weekly) so the choices were not so great 😊. It is not common that people wish for Autoimmune Encephalitis! When they finally said it is PD (and their words were 'The scan is clear – we would use it as a text book example of classic PD') I guess I was disappointed but by then I had been conditioned.

Since then my main emotion has been 'deal with it and don't stop'. Every so often I get down – usually when I see someone with more advanced PD and when I recognize that in all truth I am probably not going to have the quietest, most pain free and peaceful old age or even middle age. Especially as a control freak by nature – the idea of having to be dressed etc scares the life out of me.

The other emotion I feel relates to financial security and my emotional role being a provider for the family. I had been carefully planning and saving for retirement and paying into life insurance. The fear of being unable to save enough because of work ending way before it should and of high bills is almost as scary.

Then I stop myself and recognize that it is a waste of complete time getting down and I must get on. I want to be active when my kids hopefully get married and have grandkids and this spurs me on. I have to work now to secure our future etc etc. Luckily my religious beliefs kick

in and remind me that I know I have to do my part but that it is up to Him to decide and hopefully support me.

#### (4) Treatment

Here is a summary of the key facts of the treatment of the PD for the first year:

- **Medication** – The year started – from diagnosis with Sifrol (pramipexole) 0.375 but now stands at Amantadine 100mg \* 3 times daily, Sifrol 1.5mg, Dekinet 2mg \* 2day and Azilect 1mg. About 6 months in the drugs had not helped my significant bladder issues caused (per the doctor following an ultrasound) by the PD affecting the bladder. For this I am on Spasmex 15mg, Promnix/Tamsulosin 0.4mg.
- **Supplements** – lots of people advised lots of things and at the moment I am taking Magnesium, Vitamin B,C,D, Turmeric, Calcium
- **Mannitol** – an industrial sugar – it has been recommended by many. Although not medically proven on humans there are those who say it works wonders. For me there is no downside taking it apart from cost.
- **Diet** – I have – on discussion with a couple of nutritionists changed my diet completely – basically vegan + fish/chicken. No eggs, no red meat, no dairy and no chemical stuff (e.g. Coke), and gluten limited to Spelt (sourdough spelt in bread). Unfortunately, I am off alcohol except for a very occasional glass of wine / whiskey which I know I shouldn't really do.
- The biggest change has been **exercise** 7 days per week – I only did minimal exercise before PD but was told to by one of the physios – "You must do one of **Yoga** (I said no way), **Tai Chi** (I said no way) or **Dancing** (I said I'll do Yoga 😊)... so I do 30-35 mins Yoga every day. I am very grateful to one of my neighbors who is a Yoga teacher and has shown me a Parkinson's routine and with whom I have a weekly 1-2-1. I also go **walking** in the mornings for 5km (sometimes just fast walking, sometimes jogging) and if wet outside I use the treadmill. In the afternoon/evening I walk for about 20 minutes using **Nordic walking** sticks. Because I have been embarrassed about them, I walk inside the house around the kitchen and lounge but they are very good for my shoulders.
- I have been doing **Acupuncture** weekly as well which helps with the weak right hand side and it also helps with aches/pains caused from the exercise routine
- I started **physio** with 3 months rehabilitation which helped get me into a routine of exercise. Following this I see a physio who specializes in Fascia because I have read articles that it helps.
- I recently started more frequent choking and my voice gets weaker towards the end of the day and so I have seen a swallowing expert/speech therapist and I have **exercises for swallowing and voice exercises** to boost my vocal cords.
- Lastly **work** – all the medical teams I spoke to said I should work as normally as possible and stimulate my brain through it. I should avoid stress but work is great and I have certainly been doing a lot of that (I am much less stressed these days)

People ask me what is working and what isn't – the truth is I have no idea – I am just throwing everything at it.

### (5) Symptoms

So how has Parkinson's been in terms of symptoms. I would describe it as a lot of small stuff each of which if on its own would be ok but this is Year 1 and unfortunately it probably will go one way.

- **Stiff Right Hand Side** – my right shoulder (and arm/hand) has persistently been weaker and as the physio on Rehab told me – "it is not stuck, it is like a rock". In general my right hand arm is much much weaker although it used to be my strong arm. A number of times, my back has 'frozen' and muscle pain is intense – but this is not the norm.
- **Shakes** – sometimes better and sometimes worse – it is still very limited at this stage, most often at night and has got much better with the intro of meds. Usually in my arms it also happens in my jaw and once across my whole right hand side from top to bottom. I also often have **pins and needles** in my fingers and my right ankle area is numb pretty permanently.
- **Lost smell** – I would say this is 98% gone although I am not a scientist. This seems to have also impacted my taste but by a lesser amount and due to the diet it is really not such a big deal
- **Choking** – Now under control I had a number of choking incidents
- **Writing** – one of the first things to go was my handwriting ability – it comes and goes but is still pretty weak but is something I work hard on
- **Memory** – early on I had major major issues with my short term memory – names, forgetfulness etc totally abnormal (when asked what month my birthday was in I didn't know etc) but the doctor suggested reducing the Dekinet dosage and it seemed to come back to normality. I would say I am operating at 95% capacity – it is a big loss but manageable.
- This may sound like a joke but one of the worst symptoms has been the constant need (every 10/20 mins) to use the **toilet** – the drugs added have reduced this but still a long way from normal. At the same time and probably because of the drug side effects I am always either with constipation or diarrhea (unfortunately I haven't got them to balance with each other 😊)
- Probably most annoying is **sleep loss**. I fall asleep no problems but wake up usually at 4am and sometime a lot earlier. I am taking sleeping pills and melatonin but it is hard to get enough sleep. Apparently when I do sleep I hold sleep talking business meetings (pretty sad really)
- I have always been **clumsy**, but I am taking it to new heights of constantly dropping things – especially when I am not thinking about it.
- **Balance** – at the start my balance was terrible but has improved to almost normal

There are probably a lot more little things but so far they are under control...some of these things are often part of growing old but in this case they have marched ahead in the last year.

## **(6) Important Bit – what have I learned about PD and Myself**

I am not an expert and I am so new to PD that I have little to offer. It is degenerative so I do know it will get worse but there are additional medical options including DBS and Levadopa (which my doctor is trying to keep me off for as long as possible)

What I have learned is to try my hardest to **fight it!** I should have got into exercise and diet earlier in my life. I am a Partner of a large Consulting firm and I had a lot of stress and travel. Instead of staying healthy and dealing with things like high BP I took pills and carried on. I think (not so jokingly) that I was given a number of warnings to sort myself out and didn't listen so I was given a 'last chance'. I have a young family and I want to be around for them – in a healthy a way as possible for as long as possible as normally as possible. I have decided to do all I can and as a result have incorporated into my day (every day) Yoga, Exercise, Diet etc. I believe that if you fight it on many fronts you have a chance to hold it off but if you give into it – you are going to decline much faster. Mentally – it is hard to know that all the effort is just to keep standing still but it is what it is and that is the job. I am lucky that I have **faith** and therefore I truly believe there is a reason for everything – I don't know why and that is above my pay grade but I have to believe it is my battle and that I was given it for a reason. Almost everyone has their share of tough stuff to deal with – this is mine.

In many ways, PD has had a number of **positive benefits**. Due to the exercise/yoga/diet and a different perspective my stress levels and my blood pressure are down to about normal. I am also calmer (my family may disagree with me and the same problems at work that used to really stress me have less impact than before). **It would have been good to sort these things out before PD** but it still has had its benefits. I had lost perspective and gained it back.

I decided early on to be **open** about PD. I don't shout it out from the rooftops but I tell people. My main reason is that at some point people are going to notice and I want it to be on the table and not the thing that is never mentioned. I think it is easier for everyone. I don't like talking about it all the time but I am happy to not ignore. I find this helps! I am however (and this I have to do battle with still) very self-conscious of people noticing and have been more introverted this last period (although due to Covid it could just be that). I know it is a contradiction but hey that is life

I have decided also to **laugh** about it – and point out the funny stories when they happen like what I say when I now talk in my sleep, my kids jokes (e.g. the drink that must be my favorite is Milkshake) etc. It is not funny but it is my normal and humor helps make it more manageable.

**Listen to Advice but don't get overloaded** – lots of people have lots of advice – and I have taken much of it (especially from people who know) and I appreciate all the thoughts, but you must be true to yourself. An example for me is dancing and swimming. I just don't like these and have realized that Yoga and Walking/Jogging work for me. There simply isn't the time to do everything people suggest so you have to come up with your program. It is a daily battle and you must do something that **sticks**.

The last piece of advice I have taken on board is one from my doctor. His personal thought was to try to make PD a **part of my life and not my life**. It is easier said than done but I have taken it to heart and try!!

**I don't know how long these elements will continue...**and there are moments when it is not all as rosy especially when I see people with PD who have advanced but I hope that when I write about Year 2 (PG) I will still be saying the same.

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